



ALERT

News from the UFMCC on AIDS Legislation, Education, Research and Treatment.

HIV IN AUSTRALIA

Australia: "Best Place to Have HIV"

(by Rev. Steve Pieters)

I had heard that if you have to have HIV/AIDS, the best place to be is Australia. My February trip to Canberra, Sydney, and Brisbane confirmed this observation. Rev. Elder Nancy Wilson, Rev. Kit Cherry, Rev. Sandra Robinson and I went to Australia for the World Council of Churches Seventh Assembly (see the March-April issue of "Keeping In Touch").

In Australia, medical care is a right, not a privilege, as it is in the United States. Rev. Elder Nancy Wilson and I visited a man with aids who was hospitalized in Canberra. While this man was quite ill, the hospital facility was beautiful, the medical staff were well educated about HIV and very helpful, and the treatments available were the latest and best available.

The Australian government has worked closely with the Gay community from the beginning of the crisis to create education campaigns which deal honestly and creatively with all the issues involved. I picked up literature which was specifically designed for people as widely varied as the Aboriginal people of Australia, women, children, people who are into "S/M," and people whose literacy level is quite low. Australia's safer sex education material is not hampered by the limitations imposed by conservatives on educational material available in the U.S.

Persons with HIV are automatically eligible for their pension, and according to the Rev. Greg Smith, UFMCC District Coordinator of Australia, many take advantage of this, so that they can avoid the stress of work and concentrate full-time on taking care of themselves.

In the major metropolitan areas, the social services are plentiful for persons with HIV. There have been over 1,000 deaths from AIDS in Australia, and there are currently about 1,000 known cases in the entire continent. So persons with HIV get a great deal more personal attention.

HIV AT THE WORLD COUNCIL OF CHURCHES

In watching for how the World Council of Churches would handle HIV/AIDS, things began quite hopefully, when at the opening worship service of the World Council of Churches Seventh Assembly, Sir Paul Reeves, Governor General of New Zealand and an Anglican priest, began his sermon with a call to compassion for persons with HIV.

But beyond this first mention, and a presentation on the first Saturday of the two week Assembly, HIV/AIDS was a peripheral issue.

The presentation on Saturday was part of a theatrical review of several issues the WCC is addressing. Sketches on German Reunification, literacy education efforts in central Africa, and the women's chain of hope in El Salvador surrounded the sketch on HIV/AIDS.

Rev. Greg Smith, was one of four people involved in the sketch on HIV/AIDS. When he said, "I am a homosexual and I have HIV," he made WCC history, as the first Gay man to self-identify at a WCC event. There was a tense silence as he continued. An Australian man, Ian Hunt, movingly described his son's death from AIDS, and two other Australians spoke of the urgency of the issue. The set included the AIDS Quilt from MCC Sydney. Rev. Smith was warmly embraced by the people who approached him after the session.

At a workshop on Healing and Wholeness, I came out as a person with AIDS, which again was greeted with a tense silence from the audience, although the presenters, two women from England, thanked me profusely for my "contribution" to the workshop.

The WCC has published an issue of their magazine, "Context", dealing solely with HIV/AIDS, and a booklet on pastoral care and AIDS, which stated that while AIDS was initially associated with gay men, the issue is now primarily associated with I.V. Drug Users, hemophiliacs, prostitutes, transfusion recipients, and their sexual partners. From a global perspective, this is becoming true. However, this served as a rationale for not dealing with the issue of homosexuality and the Church. The booklet was the result of a study group established by the WCC in 1989.

MCC BRISBANE

My weekend in Brisbane was sponsored by the Queensland Positive People (QPP). Domestic airfares are very expensive in Australia, and while UFMCC paid my airfare to Australia, the local MCC's were unable to afford to bring me to each city by themselves.

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My hosts were Mr. Ian Holmes, the Pastoral leader of MCC Brisbane and Mr. Adrian Holmes, who gave a "barbie" on Saturday night for me and over 40 people from the Queensland AIDS Council (QUAC), the QPP, and MCC.

My first visit was to Brisbane Jail, along with Ian, who visits the HIV+ prisoners on a weekly basis, as well as three men from Queensland Positive People (QPP). Queensland, like New South Wales, requires HIV testing for all convicts, and those who test positive are isolated in a separate wing.

One man we met was in for a number of years, and has known he is HIV+ for several years. The other man was new to Brisbane Jail, and had just found out his test results a few days before. We talked about their goals, and what it means for them to have faith and hope in facing all they have in front of them.

Friday evening, I attended a potluck supper at the QPP House, where people with HIV come for socializing, massages, some meals, hair cuts, and other services offered by a wide variety of very committed volunteers. The house was a donation from the Sisters of Mercy.

Saturday I did workshops in the morning for persons with HIV, and in the afternoon for anyone involved in the QPP House or QUAC. There was a great deal of interest in and knowledge about alternative treatments among the persons with HIV. Among the volunteers, a discussion about death, dying and grief aroused the most passion.

One of the men challenged me for not speaking of the role of my faith in living with HIV. I explained that I had been told that in Australia, where only 2-4% of the population consider themselves religious in any sense, I should not emphasize this aspect of my journey. But I went ahead and talked about it. Afterwards, three people talked to me quietly about how important their faith was to them, and how seldom they were able to talk about it.

Sunday evening, I preached at MCC Brisbane. While the church is small, it is full of very faithful people. Julie, their Student Clergy person, is planning to move in a year to Hobarth, Tasmania to start an MCC. A number of new people showed up that night, including several who had never been to church in their life, and a couple of clergy from other denominations.

Brisbane is a beautiful city, and its people were wonderfully hospitable. In contrast to the stark modern landscape of Canberra, Brisbane felt like a real city, with layers of history, and a bustling, quite diverse population.

MCC SYDNEY

When we first arrived in Australia, Rev. Gary Walker, Pastor of MCC Sydney, was very kind in chauffeuring us from terminal to terminal, allowing us to shower and relax at his home near the airport, after a long flight from Los Angeles.

The last five days of my visit to Australia were in Sydney. Thursday night, I visited a therapy group run by a psychologist who has worked in the U.S. with George Solomon, M.D., who wrote the study of long term survivors of aids used in my pamphlet, "Spiritual Strength For Survival." In spite of his knowledge of long term survival, a number of men in the group were overwhelmed when I related my story, and asked why they had never heard about people surviving aids before.

Friday I visited the Natralya Day Center for persons with HIV. We shared a great lasagna lunch, during which there was much laughter and boisterous conversation. The government has funded this center, which is two adjoining houses where persons with aids can spend time socializing, doing art therapy, having lunch, or any number of activities. Several people talked of the tremendous contribution of the Rev. Jim Dykes to the HIV movement in Australia.

Friday night, Gary and his spouse, Peter, hosted a potluck supper where I met about a dozen men from MCC Sydney. We got into one of the best discussions about HIV I've had in a long time. There was a real sophistication to the dialogue, which ranged from survival skills, to dealing with fear and denial.

Saturday, one of the deacons of MCC Sydney gave me a rollicking tour of the city from the monorail to the Opera House and Harbor, to the old Victorian mall considered to be among the most beautiful in the world. Saturday night, a friend of Rev. Greg Smith's had me to dinner and gave me a tour of the gay pubs up and down Oxford Street.

Sunday morning, I attended the Pitt Street Uniting Church with Gary and Peter. The pastor is Rev. Dorothy McMahon, who spoke movingly of her experiences at the WCC Assembly. She is one of the most influential and respected pastors of the Uniting Church of Australia. The congregation had a number of Lesbians and Gay men, and this Sunday, there were many people from all over the world who had been at the Assembly and were heading home the next day, like myself.

That evening, I preached at MCC Sydney. There were well over a hundred people in attendance, with a number of community leaders who had never been to MCC before. Everyone was overwhelmingly gracious afterwards. They seemed very hungry for the hope represented by my testimony.

In Australia, I learned a great deal about how good conditions can be for persons with HIV. It was interesting that in spite of meeting a number of people who had been living with HIV for five years or more, and hearing about many others there, there was still quite a bit of fatalism about the disease, and genuine surprise and pleasure to hear the story of someone who actually got better. I am very grateful that UFMCC was able to send me to the WCC Assembly. I love Australia, I learned a lot.

PIETERS PROFILED FOR "REAL LIFE WITH JANE PAULEY"

Jane Pauley will be profiling Rev. Stephen Pieters, Field Director of UFMCC AIDS Ministry, and Editor of ALERT, in a segment of the NBC Sunday night program, "Real Life with Jane Pauley," scheduled to be shown on June 2.

The producers of the segment have been working for over a month, collecting footage of Pieters' activities. They filmed a session of the "Spiritual Strength for Survival 10-Step Support Group" at MCC Los Angeles, and traveled with Pieters to Pueblo, Colorado where they filmed Pieters doing grief counseling with Maryanne McPherson, the Pastoral Leader of MCC Pueblo, as well as workshops on long term survival, and death, dying and grief. The Fifth Anniversary service of MCC Pueblo, with Rev. Pieters preaching, was also filmed.

The crew spent four days with Pieters in Los Angeles filming visits to an AIDS hospice and the homes of several of Pieters' friends who have been impacted by HIV as well as a visit to the California Institute for Men in Chino, and interviews with Pieters' therapist, physician, and the Rev. Elder Troy Perry, Founder and Moderator of the UFMCC. Additional footage was shot in Pieters' home and at the gym where he works out.

On April 23, Jane Pauley flew into Los Angeles, and filmed an extensive interview with Pieters in the sanctuary of MCC Los Angeles. Following the interview, Pieters and Pauley were filmed walking down Washington Blvd. into the church. While they were waiting for the cameras to be set up, Pauley asked Pieters to teach her a tap dance. After a crash course in "flap, ball, step, hop," they burst into spontaneous tapping. The producer stated afterwards, "You can bet I caught the whole tap dancing incident on camera!" The producer later reported to Pieters that Pauley was "extremely pleased" with the interview.

Over 40 hours of film was shot, and the producers also have the videotapes of all of Pieters' interviews and public appearances. All of this will be edited down for a 7-10 minute segment.

"Real Life with Jane Pauley" airs Sunday nights on NBC-TV, at 8:30 p.m. Eastern and Pacific, and 7:30 p.m. Central and Mountain. Because of the nature of news shows, air dates are subject to change, but at press time, the segment is scheduled for the June 2 program.

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"Good" Grief: What We Can Do To Help

[by Rev. Christine Oscar; reprinted with permission from the "Oil of Gladness" newsletter, a Publication of the Grief and Bereavement Program of the GLAD District, Vol 1, #2, Feb 91. For subscription info please write to: Oil of Gladness, P.O. Box 245, Charleston, SC 29401].

We all want to help our friends and loved ones when they are grieving, but we often feel "helpless." What can we do that will be of real benefit?

First and foremost, it is important to remember that we are powerless over what the griever wants most: they want the loved one to be alive.

We need to acknowledge to ourselves that we cannot change the reality of their pain; we can only journey with them through the pain. We cannot and should not try to ease or erase the pain.

What we can do, however, is to be "present" to the grieving person. There are many ways to contribute to the quality of their journey:

- 1] Don't be afraid to touch the bereaved. Often a hug or a clasped hand speaks more strongly of your presence than can any words.
- 2] Write them a letter rather than sending a pre-printed card. The bereaved needs to feel like they are "a part of things," even though they may feel that part of themselves is now dead and gone. Simply express love and concern for them; waxing eloquent is neither necessary nor always helpful.
- 3] Let them talk. At many points, the grieving person will need to talk to supportive others. Learn to listen without interrupting and without attempting to force them to "resolve" their grief. Listen with your heart as well as your ears.
- 4] Be there to reassure them of your love when they start feeling guilty about all the things they did not get to do or say before the death. Don't try to erase their guilt or provide pat responses to "talk them out of it." (It's like trying to teach a dog to sing: you waste your time and annoy the dog.) Listen and comfort them when it is appropriate, but don't argue with their perceptions.
- 5] Remember special days. Send a note or card on occasions such as the loved one's birthday, the griever's birthday, anniversaries (including the death anniversary), Christmas or Hanakkuh, Easter.

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An Open Letter To Pastors

(by Rev. Christine Oscar)

*"Comfort, comfort my people says your
God." Isaiah 40:1-11*

- 6] Do something concrete to remember the deceased and/or honor the survivor. Donations to their favorite church, charity or AIDS program is often more appreciated than flowers. By giving something that "keeps on giving," you say that, although the loved one is not physically present, their loving, caring and influence is still part of ongoing life.
- 7] Continue to visit the bereaved on a regular basis for at least one year. Grieving is a long and extremely complicated process, and takes more than a few weeks or months for most bereaved people. Friends are frequently available early in the journey when the griever is still numb. But as the numbness gives way to the reality of loss and pain, friends have often moved on to other facets of their lives. Regular and frequent check-ins by friends over a much longer span of time are usually more valuable than overwhelming the griever early in the process.

In my own most recent journey, after my sister's suicide, the friends who kept in touch as the months wore on touched me profoundly. Their cards, letters and willingness to show the courage to ask how I was doing as the holidays and anniversaries arose eased the loneliness of the grief. And I use the word "courage" deliberately - it is not at all unusual for the bereaved person to explode with anger and other painful feelings as special days approach. Anger at themselves, the deceased, God and others is common, and those who can listen with a truly non-judgemental heart can seem few and far between. People like Mary Moore and Hope Vaughn provided a sacramental gift of presence with their phone calls and "sanity checks" because they allowed me to be me, wherever I was in the process.

- 8] Remember that each person processes grief differently and on their own timetable. Not only are individuals different; individuals' coping mechanisms in each death they encounter can vary widely as well. Try to be flexible, "meeting each person at their own map of the world" rather than trying to shape and predict their behavior.

When Jesus travelled with the disciples on the road to Emmaus, he met them where they were, listened to their feelings, and journeyed with them in their grief. He provides a model for being a friend to those confronting loss. Whether the grieving person sits and cries, stares blankly into space, frantically cleans house, isolates themselves or craves constant company, the most useful contribution to their well-being is to allow them to be exactly who they are at every point in the process. Their journey is valid however they choose to travel it, and supporting that in whatever way you can is the most important help of all.

Dear Pastors,

Whether you are a Pastor (leading a congregation) or a pastor (under-shepherd in a congregation), this letter is to you.

Although it is part of the Pastor's job description to visit the sick and the dying, this is also a ministry that can be shared with those pastors or "under-shepherds" in our congregation who feel called by God to this particular ministry. We can do much to empower our people by word and example. I remember protesting several years ago, "But I DON'T DO hospitals!!" How those words have come back to haunt me in good times and in bad; I did not come gently into this ministry, hard-healed individual that I am; kicking, screaming and frequently crying were more common in those early months.

Do people in their right (or, if we are being inclusive, right OR left) minds really choose this ministry? Sometimes yes, they do. But more often we are chosen by both God and the virtues of our call to ministry.

We now find ourselves confronted with fulfilling a ministerial task that we are often little-prepared to perform. We were trained to expect the older folks in our congregation to die - not some of our youngest members. And we weren't trained to expect so many people of all ages in our congregations to be chronically ill for months and years.

We may expect to visit an ill or dying congregant occasionally. But nothing could have prepared us in advance for so much necessary visitation as many of us now face. This is a whole different ball game with different rules than we were prepared for; but, unfortunately, none of us can escape seeing that we or others fill the designated roles due to simple ignorance.

One of the problems that frequently blocks us from dealing well with death, dying and grief is the feeling of helplessness. "What can I say?" "What can I do?" We all face those questions to some degree. In *A RUMOUR OF ANGELS: Quotations for living, dying and letting go*, Gail and Jill Perry write: On the day of his death, when his mother came into the room in the morning, the young boy spoke his last words. She asked him what he wanted for breakfast, and his reply was, "a kiss."

Ministry to the terminally ill does not require us to have all the answers. The most helpful and meaningful acts we can perform are often the deceptively simple little things: a kiss, a hug, holding a hand. All can bring more comfort, love and spiritual than the most eloquent prayers we could utter. Teaching ourselves and others the ministry of touch can take some of the fear and helplessness out of the challenges of this ministry.

I did not come from a family where much affection was shown, and am still often perceived as cold or at least distant. With my terminally ill congregants, however, this perception rarely applies: Words are so often inadequate that I often find myself become less of a talker and more of a do-er early in the process. I hug them; I wipe them down from the night sweats; I crawl up into the bed and hold them when they are shivering with chills. Many of us are afraid of holding or touching the sick; the willingness to do that is a tremendous gift. During my mother's final illness, we found ourselves running out of words and I would sit just holding her hand while she napped. I was surprised when she suddenly squeezed my hand with, tears trickling down her cheeks; and I asked her, of course, what was "wrong."

Her unexpected answer: "Haven't you noticed that none of the other kids will touch me now? They seem to be afraid they will catch the cancer from me." Her words often come back to me as I work with person with AIDS and notice how reluctant so many other people are to touch them. The ministry of touch can reassure people that they are loved and not feared - critical aspects to avoiding isolation and loneliness.

As persons committed to ministry, pastors simply MUST find ways to help ourselves and our churches through this health crisis. We can take advantage of classes and seminars that will educate us to be more equipped - and to teach OTHERS to be more equipped - to perform this unique but infinitely-rewarding ministry.

God bless us all as we journey this difficult road together. If I can help you by providing a listening ear, educational materials, or practical suggestions, please let me know. And if you can provide the same for me - let me know that, too. It will take all of our resources to provide for our churches, our clients and patients, and each other. Love in Christ, Christine.

Pneumocystis Prophylaxis: Study Suggests Lower Bactrim Dose

*(Reprinted from "AIDS Treatment News",
Vol 123, Mar 91; (415) 255-0588)*

A study of hospital records, published February 23, 1991, in *The Lancet*, has suggested that low-dose cotrimoxazole (also called Bactrim, Septra, sulfamethoxazole-trimethoprim, etc. - there are many different names for this drug) was more effective than aerosol pentamidine for preventing pneumocystis, may also help prevent toxoplasmosis, and had fewer side effects than the larger Bactrim doses used in other studies to prevent pneumocystis. And the cost of this form of pneumocystis prophylaxis, when generic versions of the drug are used, is about a hundred times less than the cost of aerosol pentamidine; the drug can cost about \$10 per year, making this therapy potentially available to everyone.

The patients studied were members of Kaiser Permanente Medical Care Program in Los Angeles. Since Kaiser patients usually get all their care from Kaiser clinics and hospitals, and obtain their prescriptions from Kaiser pharmacies, uniform records of visits and prescriptions were available. 116 patients met all the criteria for this study: consecutive prescriptions for co-trimoxazole between December 1986 and June 1988, symptoms of immune deficiency, a diagnosis of AIDS or ARC, and either previous pneumocystis and/or T-helper count under 200. All records were reviewed until June 1990, or until the patients died; no one was lost to followup. The co-trimoxazole dose used by these 116 patients was one DS (double strength) tablet every Monday, Wednesday, and Friday.

No patient had pneumocystis while on this treatment. Of the 116 patients in the study, 71 had previously had pneumocystis, and they were followed on the prophylaxis for an average of 18.5 months. Those who had not had pneumocystis previously were followed for an average of 24.2 months. By contrast, with prophylaxis, half of the patients who have had pneumocystis would be expected to relapse within eight months, according to published data from other studies; and more than half of symptomatic patients with T-helper counts less than 200, but who have never had pneumocystis, would probably develop the disease within 24 months.

These results were better than those with aerosol pentamidine. The same Kaiser center found that 10 percent of patients who had previously had pneumocystis relapsed within one year, despite 300 mg of aerosolized pentamidine once per month.

Also, there were no cases of toxoplasmosis among the 116 patients treated with the low-dose co-trimoxazole. There were cases of the disease among those treated with aerosol pentamidine (which could have no effect on toxoplasmosis, because very little of the drug leaves the lungs). However, there were not enough cases to show for sure that co-trimoxazole was preventing the disease; the fact that no one developed toxoplasmosis might have been a result of the therapy, or it might have been coincidence.

Side effects believed due to co-trimoxazole - especially rash, fever, and nausea - occurred in 28 percent of the 116 patients. But only in nine percent (of the 116) were they severe enough to require permanently stopping the drug. (In some other cases, the co-trimoxazole was stopped for seven to ten days, and then could be restarted.) Side effects almost always began within the first month if they occurred at all. In no case were they life-threatening or otherwise very severe.

PNEUMOCYSTIS PROPHYLAXIS IN CHILDREN: NEW GUIDELINES

Because the immune systems of children and infants
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are very different from those of adults, HIV infection often manifests itself uniquely in these populations. Therefore, standard treatment and prophylaxis guidelines in adults often have little relevance for infants and children. Clinicians and parents of HIV-infected children know that these children develop pneumocystis long before their T-helper counts have declined to the usual adult threshold of 200 to 300. However, almost no data exist on T-helper counts in healthy, non-HIV-infected infants and children, let alone in those with HIV infection.

A working group convened at the National Pediatric HIV Research Center at Children's Hospital in New Jersey has reviewed a series of studies of the natural history, treatment, and prevention of pneumocystis in infants and children. Their recommendations for pneumocystis prophylaxis are being published by the U.S. Centers for Disease Control in the March 15 Morbidity and Mortality Weekly Report (MMWR). The full text will be reprinted in the Journal of the American Medical Association (JAMA) on April 3. Copies can be obtained from the National AIDS Information Clearinghouse by calling 800/458-5231 after about mid-April.

Pneumocystis is a common opportunistic infection in infants with HIV. Ninety percent of young children with pneumocystis have had T-helper counts below 1500. Infants without HIV infection may have normal T-helper counts around 3,000 and as high as 5,000 - far higher than adult values; as they grow older, the counts decline to adult values. In contrast, the T-helper percentage values are comparable between children and adults. The new recommendations take these differences into account.

Although these recommendations are a vital step toward improving the standards of health care available to infants and children, advocates for children with HIV have noted that the AIDS Clinical Trials Group (ACTG), the government-sponsored clinical trials system, is conducting little research on preventing and treating opportunistic infections in children. Understanding these illnesses, and testing agents to prevent and treat them, must become higher priorities in the immediate future.

NEW TREATMENTS: VALUATION AND ACCESS

(by Kevin Armington; reprinted with permission from "Treatment Issues", Vol 5, No 3; March 28, '91)

Between the federal government and pharmaceutical companies, well over one billion dollars has been spent in pursuit of a treatment for HIV infection. Some might say squandered, since, ten years into the epidemic, a single antiviral with significant limitations -- AZT -- has been approved. It is not at all surprising that many people with HIV infection explore treatment options outside the mainstream. One study of randomly selected AIDS clinic patients in San Francisco found that 90 of 96

people surveyed had used alternative medications (22). Some of these treatments have helped people, while others have had no effect or, worse, harmful effects.

In contrast to the slow production of effective treatments by the pharmaceutical industry, alternative treatments have proliferated rapidly in the last few years. Experimental treatment publications like Treatment Issues and AIDS Treatment News, in addition to countless others, cannot cover each and every substance/therapy that is touted as promising. The purpose of this article is to empower the reader to make informed decisions about alternative therapies. The following points should be considered when gathering and evaluating information about a new treatment. Most of the individual issues raised here would not suffice as a "litmus test" to judge a treatment. Rather, a number of issues taken together will help you make an informed, responsible decision.

EVALUATING TREATMENTS:

Alternative treatments for HIV infection are sold and advertised all over the place. Many are available over the counter as "supplements" in pharmacies and health food stores. Others classified as "drugs" are sold through buyers' clubs or are administered only in a clinic or office. Mail-order ads for alternative treatments are commonly found in community publications. Sometimes public forums are held to promote a new treatment. However you hear about a new treatment, keep the following suggestions in mind:

* Do not rely on only one source to make your decision. Discuss potential treatment options with your health care providers and friends. If your doctor will not engage in a dialogue about alternative therapies, you may want to consider changing doctors or consulting with another physician. Getting a new doctor may not be so easy for people with limited or no insurance. Call some reliable hotlines and explore your options (GMHC: 212/807-6655; PWA Coalition: 212/532-0568 in New York, 800/828-3280 outside of New York; Project Inform: 415/558-9051 in California, 800/822-7422 outside of CA). Some hotlines keep doctor referral lists and others dispense information about treatments. Most importantly, do not make your decision in a vacuum.

* Beware of claims that a treatment is a "cure" or will have miraculous effects. We all want to be optimistic, but there is nothing crueler than overblown reports about new treatments. People or publications that make uninformed promises about a treatment before it has been adequately researched increase confusion and can ultimately hurt people. Claims must be substantiated by understandable information about safety in people with HIV infection and proof that the treatment has, or could have some beneficial effect.

* Prohibitively high prices for experimental treatment can be the tipoff to potential fraud. The costs of alternative treatments are absorbed by the individual, since

it is extremely rare for insurance companies or Medicaid to reimburse for treatments that are not drugs licensed by the FDA. Unfortunately, there is no shortage of charlatans willing to take sums of money for unproven and sometimes even harmful "treatments".

* Try to investigate any clinic you may visit, or have a friend look into it if you cannot do so yourself. There are several examples of clinics in the U.S. and abroad that offer expensive treatment packages. Usually, treatment requires in-patient stays for several weeks. Some of these ventures require strenuous travel to remote parts of the world. Besides financial considerations, risks may include substandard medical care and exposure to unfamiliar disease-causing microorganisms, which can strain the immune system. If no independent information is available about the clinic, it may be a negative sign. No clinic has come forth with any magic answers yet. Some, after having charged a fortune, send people home sicker than when they arrived.

INTERVIEWING THE TREATMENT PROMOTER

If you are considering trying an unproven treatment, be a smart consumer and interview the person promoting it. How much do they know about AIDS and HIV? If they reject commonly accepted theories about AIDS, are they at least familiar with these theories? What is their training? Are they interested in specific information about your medical condition, or are you treated as a faceless customer? Do they answer your questions patiently in language you understand or do they "talk down" to you? Are their explanations about the treatment overly simplistic or overly complex? Do they seem eager to foster a sense of distrust between you and your current health care providers? Is there an attempt to separate you from your current network of support? How has their treatment been evaluated so far? And what is the justification for using their treatment for AIDS?

You deserve honest, direct answers to any questions you may have. If someone suggests that you try a treatment that has not been objectively evaluated (for example published in a peer-reviewed medical journal or presented at a significant AIDS medical conference) proceed with caution. Consult with your current health care providers and friends who are familiar with AIDS. Trust your vibes. If you have a funny feeling about someone pitching a treatment, listen to your instincts and try not to act spontaneously.

MEDIA DISTORTION

There is a familiar scenario that characterizes public awareness of new potential treatments for HIV disease. It goes something like this: an item on television or in the newspaper reports a claim that a "cure" for AIDS has been discovered; many people with AIDS begin a furious quest to obtain the treatment; the initial positive results are not reproduced in further studies; scrutiny reveals that the groundbreaking reports were blown out of proportion; a sense of hopelessness sets in.

This cycle has been dubbed the "drug-of-the-month" phenomenon.

With a few notable examples, the lay media has done an inaccurate job reporting on AIDS treatments. News reports and articles on AIDS treatments tend to focus on the most sensational aspect of the story. Often the facts are either absent or utterly distorted. Inaccurate reports can create very damaging impressions in the community. In general, the lay media probably reports information too early. Splashy accounts of drugs that have great antiviral effect in the test tube make good copy, but have limited value to most people. Only about 20% of drugs make it from the laboratory to the pharmacy.

Seek out a variety of opinions to reduce possible bias. Even certain community publications have a very predictable editorial slant, calling their objectivity into question. In general, it is not a good idea to rely on one source for your treatment information. There are certainly plenty of treatment publications available free or at low cost.

ACCESS

People with AIDS and their advocates argue strenuously that a person with a serious illness has the right to make his or her own medical decisions with the advice of a physician. This right is only possible when access to treatment is assured. And when the vast majority of treatments for a disease are experimental, the issue is a critical concern.

Access to experimental drugs in clinical trials varies from drug to drug and is decided by a complex series of rituals involving FDA regulators, pharmaceutical companies, and AIDS activists. Some pharmaceutical companies have made impressive efforts to allow early access to unapproved drugs. Others have resisted access requests from advocates or provided only token programs.

Because research has moved so slowly in the U.S., the AIDS community has been forced to create an underground network that delivers experimental treatments to people willing to take a chance. Organizations like the People With AIDS Health Group in New York help people exercise their right to import drugs approved abroad but not licensed in the U.S. The FDA has adopted a policy that allows individuals to import as much as a three-month supply of an unapproved drug for personal use, with a doctor's prescription. Many safe and effective antibiotics available abroad, like clarithromycin and azithromycin, among others, have helped Americans with AIDS live longer, more comfortable lives. Unfortunately, this option is only possible for people who can raise large amounts of cash; these antibiotics can cost up to \$25/day for maintenance therapy.

Alternative treatments that are not classified as drugs are often available over the counter. There is great debate between "consumer protectionists" who

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believe that the public must be shielded from unproven treatment and people who feel that the government should not intervene in private medical decisions.

It is difficult to reconcile these views. But the good intentions of both approaches are worth pursuing. Excessive regulation of safe potential therapies by the government is counterproductive. However, in an unregulated environment, fraud may flourish. When evidence exists that a substance is harmful to consumers, some regulation may be acceptable. There may also be a role for the government in mandating that evidence be provided to consumers when claims are made about the medical benefits of alternative treatments.

CONCLUSION

Ultimately, you are responsible for what you put in your body. You deserve the best information available about any treatment -- approved or experimental -- that you are considering. Take advantage of the rich sources of information the community is generating about treatments. Above all, as a safeguard, let your health care providers know about all the treatments you are taking.

CLARITHROMYCIN: ABBOTT SEEKS COMPASSIONATE ACCESS FOR MAC

*(by John S. James; reprinted with
permission from AIDS Treatment News,
#124; April 5, '91; 415/255-0588)*

Abbott Laboratories has contacted the U.S. Food and Drug Administration (FDA) and proposed a draft protocol for compassionate use of clarithromycin for persons with AIDS who have mycobacterium avium complex (MAC, also called MAI).

Clarithromycin, a new broad-spectrum antibiotic approved in 20 countries but not yet in the United States has quickly become a major concern of treatment activists. MAC is one of the most widespread opportunistic infections, and conventional treatment (usually a "cocktail" of four or five antibiotics) is often unsatisfactory. Early research results and practical experience both suggest that clarithromycin is much more promising than any of the standard treatments. Persons with MAC have imported the drug, but it is expensive, and often financially burdensome or unavailable, since unapproved drugs are seldom covered by insurance. It is hoped that some form of compassionate treatment access can fill the gap until the drug can be financed in the same way as other medical care. We do not know how long it will take for Abbott's preliminary proposal for compassionate use to be completed and implemented.

Clarithromycin was first developed for uses not related to AIDS. For these purposes the drug is less critical, because other satisfactory treatments are available. Clarithromycin has the advantage of broad-

spectrum activity; according to Abbott's April 1 news release, it "has been shown to be active against all significant respiratory pathogens as well as against the full range of community-acquired skin and gastrointestinal infections."

For information about obtaining the drug now, call the PWA Health Group, 212/532-0280, or LABC/Staying Alive, 213/748-1295.

ddI WARNING: DON'T TAKE DAPSONE AT SAME TIME

*(Reprinted with permission from
AIDS Treatment News; #125)*

The U.S. Division of AIDS has issued a warning to physicians that patients using ddI and also using dapsone, a drug for pneumocystis prophylaxis, should not take the drugs within two hours of each other. The problem is that dapsone requires an acid environment in order to be dissolved; but ddI cannot tolerate an acid environment, so it is taken with a buffer to neutralize stomach acidity. The lack of acidity causes the dapsone not to be absorbed.

Jacobus Pharmaceutical Company, the manufacturer of dapsone, brought the problem to the attention of the Division of AIDS after several cases of pneumocystis were found in patients who were taking both drugs. At least 11 cases of pneumocystis have occurred within 10 to 130 days after starting therapy with the two drugs together.

This problem could also affect other drugs which require an acid stomach - for example, ketoconazole.

The following recommendation is included in Safety Memo 013 of the Division of AIDS:

"Recommendation: The Division of AIDS and Jacobus Pharmaceutical Company recommend that clinicians contact all patients who are receiving both ddI and dapsone by telephone and advise them to take dapsone two hours prior to ddI."

The memo also says that if patients cannot take dapsone at least two hours before ddI, they should wait until two hours after. The two drugs should not be taken within two hours of each other.

(Enclosed for your convenience is an offering envelope for the UFMCC AIDS Ministry. Thank you for your support!)

****This issue of ALERT has been delayed due to preparations for General Conference!**